UNDERSTANDING RESEARCH ETHICS

6

CHAPTER OUTLINE

1. Why Do We Care about Human Subjects Protection?
2. How Do We Follow Research Ethics and Ethical Guidelines?
   a. Respect for Persons and Informed Consent
   b. Nonmaleficence and Beneficence
   c. Justice
   d. Including Participants in Co-Constructed Research
3. Ethics in Reporting Findings
4. Who Oversees Research Ethics? Institutional Research Boards (IRBs)
5. How Do We Maintain Ethics through all Research Phases?
6. So What?

KEY TERMS

Anonymity
Assent
Belmont Report
Beneficence
Confidentiality
Deception
Ethical research

Human subjects protection
Informed consent
Justice
Legitimation
Member checks
Nonmaleficence
Nuremberg Code

Participatory action research
Relational ethics
Representation
Research ethics
Respect for persons
Vulnerable populations

CHAPTER OBJECTIVES

1. To understand the standard, proper, and ethical way in which to conduct the many types of communication research
2. To understand how to conduct research that is respectful to participants, the research community, and society
3. To understand how to conduct research that has appropriate legitimation and representation and appropriately represents multiple voices

▼ # Why Do We Care about Human Subjects Protection?

research ethics
The specific principles, rules, guidelines, and norms of research-related behavior that a research community has decided are proper, fair, and appropriate.

ethical research
Research that is designed and conducted validly, reliably, legitimately, and representatively, and protects a research participant's rights.

human subjects protection
Ethical research rules that refer to the guidelines that are followed to ensure the protection of people (participants) being studied.

Nuremberg Code
The first set of principles outlining professional ethics for medical researchers, which forms the basis for today's research ethics codes. It specifically required voluntary consent among research participants, and was the first international standard for the conduct of research.

Research ethics refer to the specific principles, rules, guidelines, and norms of research-related behavior that a research community has decided are proper, fair, and appropriate. In short, **ethical research** protects a participant's rights (Murphy & Dingwall, 2001), but it does more than that. Ethical researchers also design and conduct research that is valid, reliable, legitimate, and representative. In this chapter, we will discuss the history of research ethics and human subjects' protection, provide examples of ethics breaches, discuss some major concepts behind research ethics, explain the role of Institutional Research Boards (IRBs), and teach you how to ensure that your research follows ethical guidelines. We'll discuss ethics from the points of view of both interpretive and positivist paradigms, and address the specific applications of ethical research principles in both qualitative and quantitative research.

The research ethics codes that are adhered to by most researchers were written as a result of abuses and violations of ethical principles by many researchers over many years, worldwide. You might hear these rules referred to as **human subjects protection**, which refers to the guidelines we follow to make sure we are protecting the people we are studying (people whom we, in communication studies, typically call our "research participants"). Our field of Communication also has its own ethical views, guidelines, and norms that are specific to the types of research we conduct, which we will discuss throughout this chapter.

The history of human subjects protection in research really begins with the Nazi medical war crimes during World War II. These abuses were particularly heinous, including—in the name of research and science—conducting medical experiments on concentration camp prisoners. These medical experiments included such appalling acts as injecting people with gasoline, live viruses, and poisons; forcing them to sit in ice water or freezing temperatures for hours; forced sterilization; depriving them of food and water; dissecting their brains; and burning them with bomb material. After the war, former Nazis were indicted before the War Crimes Tribunal at Nuremberg. One of the outcomes of this trial was the **Nuremberg Code**, which was the first set of principles outlining professional ethics for medical researchers, and which forms the basis for today's research ethics codes in both medicine and in the social sciences. The Nuremberg Code specifically required voluntary consent among research participants, and was the first international standard for the conduct of research (Annas & Grodin, 1995). We'll further discuss the ethical standards and principles for research shortly, but first let's take a look at some other examples of violations of rights of research participants in our own country.

The most famous violation in United States history might be the Tuskegee Syphilis Study, a long-term study of black males conducted in Tuskegee by the U.S. Public Health Services. This research began in the 1930s and continued until 1972. The researchers studied over 400 African-American men with syphilis and 200 without syphilis. They were recruited without informed consent

and were misled about the nature of the study and what procedures would be done on them. Most appalling, they were not informed of the complications experienced by others in the study. (The death rate among those with syphilis was twice as high as among the control group.) In addition, in the 1940s penicillin was found to be effective in treating syphilis; the study continued and the men were not informed about the possible treatment. Investigation into this research abuse led to the U.S. government's oversight of ethics for federally supported research projects (Thomas & Quinn, 1991).

In 1963, studies were conducted at New York's Jewish Chronic Disease Hospital to understand whether the body's inability to reject cancer cells was due to cancer or to debilitation. To test this, they injected live cancer cells into patients. The consent process did not inform the subjects that they were about to be injected with cancerous cells, because the researchers didn't want to "unnecessarily frighten them." The researchers were later found guilty of fraud, deceit, and unprofessional conduct (Edgar & Rothman, 1995).

From 1963 to 1966, at the Willowbrook State School in New York, an institution for "mentally defective children," researchers wanted to study the natural history of infectious hepatitis. Newly admitted children were deliberately infected with the hepatitis virus. Parents gave consent, but since the hospital was only admitting patients who were in this program, this wasn't really freedom of consent because parents didn't have an alternate choice if they wanted treatment for their children (Krugman, 1971).

Don't think all research abuses and dilemmas have taken place in medical research. There are many examples of ill-treatment of research participants in social science research as well. The most famous example may be the Milgram obedience to authority experiment, in which the researcher used bogus electric shocks to measure the extent to which people would submit to authority to inflict pain on another person. Since the shocks were not real, the ethical criticism was not about the physical pain seemingly inflicted on the recipient of the shock, but on the emotional pain and duress inflicted on the research participants, who were led to believe that they were inflicting severe pain on other people (Kelman, 1967).

In a study closer to what communication researchers might investigate, in 1955 researchers in Wichita studied jury deliberations in an attempt to examine group decision making and negotiating. This study was also ethically criticized because participants were not told they were being researched, observed, and videotaped, and, as part of the social institution of the jury process, had reason to believe their communication was private and confidential (Kimmel, 1988).
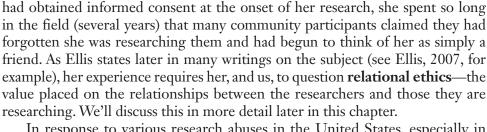
Many qualitative and ethnographic social science researchers have been criticized for covertly observing people without their knowledge or consent. Humphrey's (1970) study of homosexual encounters in public restrooms and Kotarba's (1979) study of sexual activity in a public jail visiting room are two striking examples, especially given the deeply personal nature of the behaviors under observation. Even seemingly innocuous observations of people's day-to-day lives can be criticized if people don't know, or forget, they are being observed. Carolyn Ellis, for example, published her research of two Eastern Virginia fishing communities in her book *Fisher folk: Two communities on Chesapeake Bay* (Ellis, 1986). While she

had obtained informed consent at the onset of her research, she spent so long in the field (several years) that many community participants claimed they had forgotten she was researching them and had begun to think of her as simply a friend. As Ellis states later in many writings on the subject (see Ellis, 2007, for example), her experience requires her, and us, to question **relational ethics**—the value placed on the relationships between the researchers and those they are researching. We'll discuss this in more detail later in this chapter.

In response to various research abuses in the United States, especially in medical research, in 1979 the U.S. government crafted a document titled "Ethical Principles and Guidelines for the Protection of Human Subjects," commonly known as the **Belmont Report**. The Belmont Report serves as the cornerstone of ethical principles upon which federal regulations for the protection of human research participants are based. Our human subject protection guidelines are based on the three principles of the Belmont Report: respect for persons, beneficence/nonmaleficence, and justice (Murphy & Dingwall, 2001).

relational ethics
The value placed on the relationships between researchers and the people they are researching.

Belmont Report
This document serves as the cornerstone of ethical principles upon which federal regulations for the protection of human research participants are based.

How Do We Follow Research Ethics and Ethical Guidelines?

Respect for Persons and Informed Consent

The first principle, **respect for persons**, states that research participants should be treated as autonomous agents—that means they are independent, self-governing, and capable of making decisions for themselves as long as they are given sufficient information to make those decisions. This principle forms the basis for **informed consent**. In the consent process, people are to be given full information about the research, both risks and benefits, and allowed to make the decision for themselves if they will participate. A proper consent procedure should include the participant's right to withdraw from the study without penalty, the focus of the study and methods to be employed, statements surrounding confidentiality, and a signature of both the researcher and the participant (Creswell, 2007). The informed consent process assumes that the research participant is competent to consent—that, if he or she is given all relevant information, he or she will be able to comprehend the information and be able to agree to participate in a voluntary manner that is free from coercion. As part of the informed consent process, the researcher must disclose all relevant information to potential participants, including the purpose of the study, the nature of the research procedure, reasonable alternatives to the proposed intervention (if the intervention provides a service or treatment such as in medical research), and any risks, benefits, or uncertainties of the intervention. The process also insists that participants can change their mind and withdraw at any time (which can be more than a little nerve-wracking in long-term ethnographic research, in which the entire research study could be compromised if the participant changes his or her mind). However, withdrawing from research is always the participant's prerogative. We have included a sample consent form in Appendix B of this textbook.

respect for persons
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informed consent
This process assumes that the research participant is competent to consent—that, if he or she is given all relevant information, he or she will be able to comprehend the information and be able to agree to participate in a voluntary manner free from coercion.

There are a few exceptions to required informed consent, however. If the research could not possibly be carried out with informed consent, and if the risk to participants is minimal, it might be ethical to waive informed consent. An example in a communication studies project might be one in which participants are being interviewed about illegal drug use. In this case, signing a consent form (and putting their name on a legal document if their participation implies admission to drug use) would be more harmful than a waiver of consent. Typically, the researcher would obtain oral consent, but not signed consent. Sometimes, in an ethnographic research study, researchers are observing individuals in public places in which it would be impossible to obtain consent from everyone present. If the research was being conducted in a place sufficiently public that there is no reasonable expectation of privacy, consent is usually not required or obtained. Examples of this type of research might include studying anonymous chat room communication or observing nonverbal communication (from a distance) at a shopping mall. Of course, even if consent can be waived, this doesn't mean that the researcher is exempt from treating participants in an ethical manner.

There are also other types of communication research that are exempt from obtaining informed consent. Informed consent is, obviously, obtained from people who are research participants, typically defined as a living individual about whom a researcher obtains information through an interaction with the person. A research participant might also need to give consent to let the researcher have access to personally identifiable private information (e.g., medical records), or to let a third-party participant give information about him or her (e.g., if you are interviewing a doctor about a patient, the patient has to give consent to let the doctor talk about him or her) (Mertens & Ginsberg, 2008). In other words, when a communication scholar writes a rhetorical analysis of Barack Obama's latest speech, since Obama is a public figure, his speech is considered a public event, and if the researcher has not obtained that data through interaction with Obama, informed consent is neither possible nor necessary. Similarly, analysis of diaries or letters of a deceased historical figure does not require informed consent. However, analysis of letters from a person who is still alive might—or might not—require informed consent, as might a study of Internet blogs or videos posted to Facebook, if that study uses information in a way that identifies the author of the blog or video. In fact, the proliferation of blogs and other Internet-based communication raises new ethical considerations. Many scholars now say that if information is posted to an online community that is password protected, it should be considered private rather than public information (Parry, 2011). At the same time, some argue that social media posts on open-access platforms, such as Twitter, are tantamount to broadcasting—and as public information they are no more subject to informed consent than the content analyses described above. Many communication scholars are currently debating the issues of consent, confidentiality, and anonymity in online environments, and not all agree on what Internet-based information is public and what information is not.

In fact, the use of online information as data is a hot button right now. A 2011 article in the *Chronicle of Higher Education* (Parry, 2011) reported on the use by Harvard sociologists of 1,700 Facebook profiles of students at their university. On the "pro" side, researchers say that the research they are doing can lead to important social information about culture and communication and that steps were taken to

minimize the risk of privacy violations. On the "con" side, critics of this research say that deceptive practices were used to access the Facebook information in the first place (research assistants added in people who had set restrictive privacy settings but were their own "friends" and so were available to them), and when the researchers shared the database of information with other researchers, the students' privacy was not sufficiently protected. Those with access to the report may have been able to figure out who some of the people were by comparing information from the Facebook profiles (hometown and major, for example) with the Harvard student database. Critics further say that the fact that people whose information was included were not informed of the project and didn't give consent is a breach of research ethics. Certainly, it's unclear whether information posted online in such settings is considered public or private information, but we suggest you always make your decision on the side of caution.

Therefore, we argue that there really is a bottom line issue here—if the information is publically available (published someplace, including online), and if there is not a reasonable expectation of confidentiality, you should obtain consent if possible, cite appropriately at all times, and maintain ethical standards when using the information. If the research participant can be identified by you, regardless of whether you keep that identification confidential, and if obtaining informed consent is possible, you should obtain it. If it's not possible to obtain consent, you must make sure risks are minimal and participants are treated ethically. Sometimes, this can be accomplished by using aliases or codenames, reporting information only in aggregate (combined with other people rather than individually), leaving out identifying information, or otherwise maintaining participant confidentiality when citing Internet-based communication. Of course, researchers must always abide by decisions on consent and exemptions from consent made by their Institutional Research Boards (IRBs). We will discuss the difference between confidentiality and anonymity shortly.

Third-party information is frequently obtained in health communication research, in which a health-care professional might be asked questions about a patient. In this type of research, consent must be obtained from both the provider and the patient. While somewhat beyond the scope of this textbook, there exists a whole other set of ethical guidelines concerning the handling of medical records. The privacy laws associated with the Health Insurance Portability and Accountability Act of 1996—or HIPAA (pronounced "hip-ah") —apply to the handling of medical records that may associated with health communication research and interventions. Researchers working in this domain or who collaborate with those in the medical field should consider reading up on HIPAA regulations concerning privacy, which in some instances are even more strict than the general standards associated with social research.

Sometimes, simply obtaining informed consent from participants isn't enough. As Ellis's study of fishing villages illustrates, when we are in the field for long periods of time, or when we are researching cultures in which we ourselves participate, we must also be attuned to our relationships with our research participants so that we don't use friendship to obtain information in ways that might be harmful or hurtful to them. As Ellis (2007) stated in musing about her

experience, "the problem comes not from being friends with participants but from acting as a friend yet not living up to the obligations of friendship" (p. 10).

There are some potential participants who may not be fully able to decide for themselves if they want to take part in research. These people are referred to in human subjects protection terms as **vulnerable populations**, and they are defined as "persons with diminished autonomy" (NIH Office of Extramural Research, 2008). Children, people with cognitive impairments, older adults, people with severe health problems, employees, and students (yes, students) are considered vulnerable populations. Most of the characteristics are obvious, but why would employees and students be vulnerable populations? Both are susceptible to coercion—by employers or professors—to participate, and safeguards must be taken to make sure that their consent is truly optional. Some vulnerable populations, such as children, must be given additional protections in research, such as needing permission of a legal guardian overseeing their care in order to include them in research. However, researchers must give everyone, regardless of diminished autonomy, the opportunity to choose (to the extent they are able) if they want to participate in the research. This might mean that if you want to interview a person with Alzheimer's disease, you would first obtain legal consent from his or her guardian, then obtain **assent**—the permission of the person with Alzheimer's to conduct the interview just prior to doing so.

There are specific ethical challenges in conducting ethnographic, autoethnographic, and narrative research among certain vulnerable populations. Many autoethnographers have written about relationships with friends or relatives who are deceased. Obviously, it is impossible to obtain consent or assent from a person who is no longer alive, and IRB rules would exempt such studies from IRB oversight since the research subjects are not living participants. However, Ellis (2007) maintains that such writing should be held to even higher ethical standards. She reminds us that the dead cannot provide consent nor be libeled, and such research incites positive and negative emotions on behalf of the writer, as well as the audience.

Nonmaleficence and Beneficence

Nonmaleficence (no avoidable harm should be done to participants) and **beneficence** (the outcome of research should be positive and beneficial) maintain that research is ethical if the "benefits outweigh the potential for harm" (Murphy & Dingwall, 2001, p. 340). The types of risk-benefit analyses used in biomedical research would be helpful, but this is usually not feasible in communication research. Sometimes, participants may experience emotional or psychological harm that cannot be measured or may be delayed. The greatest risk in ethnography, for example, comes after publication, as a result of what is and what is not printed (Cassell, 1978; Murphy & Dingwall, 2001; Wax & Cassell, 1979). Unlike studies in more quantitatively oriented social science research, anonymity may not be possible in ethnography. It is difficult to gauge a subject's possible feelings of shame or embarrassment due to self-disclosure. To combat this phenomenon, it has been suggested that subjects have an opportunity to share in production of a work or be able to provide a response to printed material.

vulnerable populations
Persons with diminished autonomy; specifically, children, people with cognitive impairments, older adults, people with severe health problems, employees, and students.

assent
Permission obtained from individuals with limited capacity to consent (e.g., minors), allowing themselves to be included as participants in research studies. Assent occurs after informed consent (permission to participate) is obtained from a person who is responsible for the well-being of the participant, and should occur as near as possible in time to the research intervention.

nonmaleficience
No avoidable harm should be done to participants.

beneficence
The outcome of research should be positive and beneficial.

The principle of beneficence refers to making efforts to secure the well-being of research participants, or to maximize the possible benefits of the research and minimize its possible harm. The key to this principle is, since all research has both risks and benefits, to make sure they balance or that benefits outweigh potential harms. Benefits to research might include a monetary incentive for participation, a relationship with the researcher or other participants, knowledge or education gleaned from participation, or the opportunity to do good for society. The community of science also believes that it is important to make sure that the research is sound, and will make a sufficient contribution to knowledge that justifies any risks that may be incurred by the study participants.

The principle of beneficence says that no individual shall be intentionally injured in the course of the research. In communication studies research, we typically don't inflict physical harm on participants. However, our research might inflict emotional or social harm, such as embarrassment, shame, or stigma. Our research must always protect a participant's right to privacy through anonymity or confidentiality of responses, unless the participant gives permission to waive confidentiality. **Anonymity** means that no one, including the researcher, can connect the participant's responses with his or her identity. An example of anonymous research is a survey in which participants do not release their names or chat groups in which people don't use their real names. **Confidentiality** means that, although the researcher knows what each participant said (or can find out this information), the participant's identity is kept secret when reporting or writing up the findings. Sometimes, for example, participant confidentiality is ensured by providing aliases in the final report (Creswell, 2007). By many state and federal laws, a researcher must disclose information indicating a risk of harm to others (homicidal thoughts), a risk of harm to themselves (suicidal thoughts), or child or elder abuse. There may be instances in a research setting that require the interviewer/observer to report illegal activity divulged by a participant (Creswell, 2007), particularly if the information disclosed is pertinent to an ongoing legal investigation.

There are times, especially when conducting qualitative research such as narrative or autoethnographic research, when anonymity and confidentiality are not possible or desirable. If this is the case, participants must be told this up front, and the researcher should follow two other related principles: Do no harm when publishing the results, and be attentive to causing discomfort in the study. There are times when a research finding *could* be reported but *must not* be reported if doing so could cause harm to a study participant.

Most researchers consider it highly unethical to deceive a participant for the purpose of gaining information, such as gathering information secretively (except when you are observing public behavior, as we discussed earlier) (Creswell, 2007). However, if an extreme instance makes it necessary to deceive the participants, you must lessen the adverse effects from the **deception** by, after the fact, dehoaxing them (tell them what you've done), debriefing them (discussing the research with them), and desensitizing them (if they have acquired negative information about themselves in the course of the research, make sure they know it is not true).

While researchers are rightly concerned about our research participants, we also might safeguard against potential harm done to researchers themselves. Researchers can be adversely affected by improper boundaries between themselves

anonymity
No one, including the researcher, can connect a participant's responses with his or her identity.

confidentiality
The identity of participants is kept secret when researchers report or write up their findings.

deception
A violation of the right to informed consent that may sometimes mislead participants as to the study purpose.

and their participants, and many qualitative researchers report ethical uneasiness with the levels of affinity they develop with study participants. These feelings of closeness to the subject of the study may lead to feelings of care and protectiveness, which may in turn bias interpretations of the behaviors under observation. Qualitative researchers must also balance their own self-disclosure to participants in interview situations. Some researchers report feelings of vulnerability, guilt, and emotional exhaustion resulting from their time in the field. Other researchers not directly involved with participants, but studying data about sensitive or disturbing topics, report experiencing emotional problems resulting from their research (Dickson-Swift, James, Kippen, & Liamputtong, 2007). Dickson-Swift and colleagues (2007) suggest that researchers vulnerable to these challenges utilize a support network of colleagues and researchers with whom to debrief their experiences.

Justice

The last tenet of the Belmont Report is the principle of **justice**. This principle takes a slightly different point of view of research participants, because it looks at who is included as research participants and who is excluded. This principle says that all classifications of people (race, ethnicity, gender, age, etc.) should receive equal treatment in terms of risks and benefits associated with the research. Certainly, including only people of one ethnicity in research that subjects them to harm is not just. However, excluding people of a certain ethnicity in research that might help them is equally unjust. Risks and benefits should be distributed fairly and without bias, and people should be included or excluded in research only for reasons that have to do with the research question or hypothesis.

Like the Tuskegee study discussed earlier, medical experiments provide the most obvious examples of ethical breaches in this area. Bayer and Tadd (2000) reviewed research protocols of 155 medical studies that were relevant to elderly people and found that over half excluded people over a certain age without justification, failing to test medical interventions on sections of the very populations for which they were intended! In social science research, similar breaches can occur. Becker-Blease and Freyd (2006) argue that many policy decisions on child abuse are made on insufficient information because researchers are reluctant to interview survivors of abuse, for fear of causing emotional harm. They suggest that researchers are inflicting even more harm on abuse survivors by inadequately studying this experience.

Another consideration related to justice is including participants with physical or cognitive impairments in research, especially those participants whose impairments may affect their communication abilities, such as in the case of people with brain damage or neurological disease (Paterson & Scott-Findlay, 2002). It is often difficult to include people with communication impairments in research appropriately while overcoming those very impairments in the data collection process. In these instances, it is not unusual for proxies, such as nurses and family members, to assist in facilitating an interview. While the service of a proxy can be helpful, the proxy's own bias in making decisions for the subject is often unavoidable. Informed consent procedures may need to be modified so

justice
All classifications of people (race, ethnicity, gender, age, etc.) should be equally subjected to the risks and benefits of research, and people should be included or excluded only for reasons that have to do with the research question or hypothesis.

the research participant can understand the instructions. Researchers may also need to be attuned to participant distress, participant fatigue, misrepresentation of research questions, and irregular or conflicting responses from the participant.

In regard to justice, when designing a study and analyzing and writing results, researchers are dissuaded from prioritizing the perspective of the elite or privileged while downplaying the views of the less fortunate (Guba & Lincoln, 1989; Marshall, 1985; Murphy & Dingwall, 2001; Sandelowski, 1986; Silverman, 1985). It is important to depict accurately all parties involved (Murphy & Dingwall, 2001).

Including Participants in Co-Constructed Research

legitimation

The question of who can represent another person in narrative writing.

representation

Fully understanding the lived experiences of research participants and including the multiple realities, interpretations, experiences, and voices emergent from all individuals and all angles.

Researchers, especially those following the interpretive paradigm (see Chapter 2), are also concerned about issues of **legitimation** (Who can speak for these people?) and **representation** (How can you speak for these people?). Representation refers to understanding fully the lived experiences of research participants and including the multiple realities, interpretations, experiences, and voices emergent from all individuals and all angles. One challenge is to ensure that the people and context studied are adequately and sufficiently represented, and that rigorous attempts are made to include their own voices and interpretations. Methods that directly include—and help researchers more fully understand—participants' voices and interpretations might include interactive techniques such as interactive interviewing, interactive focus groups, co-constructed narratives, or close observation over a long period of time (which we will discuss later in this book), which allow study participants to give their own accounts of their own experiences. Other advantages of coauthored methods include the possible avoidance of obtaining consent (since participants are also researchers), alleviation of concerns about offending subjects, and less likelihood of research participants changing their minds about participating (Denzin, 2003; Ellis, 2007).

member checks

The process of providing study participants with the research findings, and giving them the opportunity to voice agreement or disagreement with the research as reported.

Qualitative researchers should also ensure that they are representing the voice of their participants by conducting **member checks** at the conclusion of their study. Member checks consist of a process of providing study participants with the research findings and giving them the opportunity to voice agreement or disagreement with the research as reported.

Social science researchers have been increasingly concerned about the moral ethics of conducting research among traditionally marginalized and stigmatized groups of people in ways that might exploit or take advantage of them. For example, some feminist researchers argue that proper interpretation can only be achieved by cooperation between the researcher and participant. Many feminist ethnographers, and others, subscribe to methods of reciprocity in researcher–participant relationships (Murphy & Dingwall, 2001). The traditional researcher–participant relationship is one of hegemonic power, in which the researcher holds power over the people he or she is studying, simply by virtue of the fact that the researcher is in charge of the study, the methodology, the analysis, and dissemination of the findings. In addition, in more traditional forms of research, researchers, in essence, speak for the participants, in effect silencing their voice and assuming a professional stance in which the researcher's opinion of the participant's point of view might be presumed to be more valid than the

participant's own opinions. In this context of "narrative privilege" (Adams, 2008, p. 180), researchers hold what's called "legitimate power" over non-researchers in their narratives. In other words, stories with stronger perceived cultural value—traditional researchers' stories—are considered to be more important or more valid than other types of stories—stories of people from marginalized groups. In addition, the narrative skills and ability traditional researchers have also hold legitimacy over people who cannot write or access textual forms.

More researchers are moving toward equalizing this power differential in their relationship with research participants by making a conscious effort to include the voice and feedback of all system of care participants, and by seeking to understand participants' own meanings and interpretations and using these interpretations of reality rather than their own. More recently developed methodologies represent multiple voices in a collaborative, co-constructed manner that lets research participants have a say in how the research is conducted by exerting or influencing control over the conversations. **Participatory action research** is an example of one methodology that attempts to break down power relationships between the researcher and the researched by letting the stakeholders define the problem and work toward solutions; inviting participants to formulate the original questions, design the methodology, facilitate the sessions, and lead the analysis efforts; and moving the research into the community. In a study by Ozer and Wright (2012), participatory action research was used to examine whether student-led participatory research increased autonomy in two urban secondary schools. It was suggested that this type of research led to unique interactions between students and adult faculty and expanded areas of student influence within these schools.

participatory action research
An example of one methodology that attempts to break down power relationships between the researcher and the researched by letting the stakeholders define the problem and work toward solutions; inviting participants to formulate the original questions, design the methodology, facilitate the sessions, and lead the analysis efforts; and moving the research into the community.

Ethics in Reporting Findings

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As you will discover in coming chapters, social scientists aim to test research questions and hypotheses through their observations and often times through the analysis of data. Scholars have argued over the years that academic journals tend to have a bias against non-significant findings —this is to say that when the analyses don't turn out as the researcher expects, this is sometimes interpreted as an indication that the work is deficient and the piece is deemed unpublishable by reviewers and editors. Rosenthal (1979) and others have called this the "file drawer" effect. Since non-significant findings often go unpublished, there may be a temptation to "massage" data in such a way as to suggest that they support certain positions. There may also exist the temptation to engage in "HARKing," or hypothesizing after results are known (Kerr, 1998). In such instances, researchers examine the data first, then pretend that they anticipated the results all along.

Do not do this. Both of these research practices are widely considered unethical, and can lead to serious academic and professional consequences. As we will see in later chapters, readers tend to have expectations of what good data reporting looks like. Dishonest reporting also produces knowledge that is fundamentally flawed, since the data don't actually support the claims made by the researchers. Data analytic issues are largely policed by journal editors and

reviewers. When it comes to ethics in research procedures, ethical practices are supervised by entities called IRBs.

▼ Who Oversees Research Ethics? Institutional Review Boards (IRBs)

Most academic research is overseen by university IRBs (Institutional Research Boards). Simply put, IRBs act as gatekeepers to research conducted by researchers affiliated with their university. They have a three-fold purpose: to protect the university from legal repercussions of conducting research deemed unethical, to protect the university from financial (and legal) sanctions imposed by the federal government and other funders on research deemed unethical, and to protect research participants from unethical practices in research. IRB board members usually consist of a cross-section of university faculty, and might also include legal and administrative representatives. All faculty—and some student—research must be submitted to the IRB for approval before being conducted. Even if the IRB will consider the research to be exempt from human subjects protection, most university IRBs want to make that ruling themselves. Student research conducted as part of a class project is usually exempt from IRB oversight because the students are considered to be under the oversight of their professor. However, if the research may later be submitted for publication, since peer-reviewed journals usually require IRB oversight, IRBs usually recommend that it be submitted to them anyway. Student research conducted for thesis or dissertation purposes is usually required to be submitted to the IRB.

Even if you are not conducting research under the authority of a university, you might still be subject to IRB oversight. Hospitals, research institutes, community agencies, and other organizations that conduct research frequently have their own IRBs.

Often, IRBs approve research projects quickly and efficiently. Criticism of IRBs and the IRB process occur when they don't. IRBs, at times, require researchers to change their method or procedures, and some researchers see this as a threat to academic freedom and a form of censorship, especially since most university faculty are required to conduct and publish research (Lewis, 2008; Lincoln, 2000). Critics of IRBs and other research gatekeepers claim that such censorship serves to suppress more innovative forms of research (Lincoln, 2000; Lincoln & Cannella, 2004).

▼ How Do We Maintain Ethics through all Research Phases?

Ethical considerations in research do not stop when you are done with data collection—ethical researchers make ethical decisions at every stage of the research process, from study design to publication of findings. Booth, Colomb,

and Williams (1995, pp. 255–256) address ethical decision making in all stages of the research process in their "7-commandments" of ethical research. They say that ethical researchers:

1. Do not steal by plagiarizing or claiming the results of others.
2. Do not lie by misreporting sources or by inventing results.
3. Do not destroy sources and data for those who follow.
4. Do not submit data whose accuracy they have reason to question.
5. Do not conceal objections that they cannot rebut.
6. Do not caricature those with opposing views or deliberately state their views in a way they would reject.
7. Do not write their reports in a way that deliberately makes it difficult for readers to understand them, nor do they simplify that which is legitimately complex.

To borrow from the NRA's (National Rifle Association) familiar saying about gun control: "Research doesn't harm, researchers do." Research findings, both qualitative and quantitative, can be manipulated, misinterpreted, and misrepresented. Despite the desire of quantitative positivist researchers to remain objective, researchers of all paradigms should admit that it is impossible to remain completely objective in any research. Quantitative researchers address this dilemma by designing studies that are as objective as possible. Qualitative researchers, in contrast, address it by admitting their subjectivity, and taking that into account when analyzing their results (Hewitt, 2007). All researchers use rigorous, acceptable, analytical methods to determine what their data means. Quantitative researchers use appropriate statistical and systematic techniques to analyze their data. Qualitative researchers take into account interpretation and context as they acknowledge their role in the construction of knowledge (Hewitt, 2007).

So What?

In summary, it is our responsibility as researchers to ensure that: our research is properly designed, scientifically sound, and yields valid results; we do what we say we're going to do; the study is approved by an IRB and conducted according to protocol; informed consent is appropriately obtained; the rights and welfare of the participants are monitored throughout the study; the risks and benefits of the research are positively balanced; participant anonymity and confidentiality are appropriately maintained; and all participants—including those from underprivileged and marginalized populations—have an opportunity to have their voices and interpretations fully represented. The bottom line: Researchers are accountable and must show respect to colleagues in their profession and society at large.

Glossary

Anonymity
No one, including the researcher, can connect a participant's responses with his or her identity.

Assent
Permission obtained from individuals with limited capacity to consent (e.g., minors), allowing themselves to be included as participants in research studies. Assent occurs after informed consent (permission to participate) is obtained from a person who is responsible for the well-being of the participant, and should occur as near as possible in time to the research intervention.

Belmont Report
This document serves as the cornerstone of ethical principles upon which federal regulations for the protection of human research participants are based.

Beneficence
The outcome of research should be positive and beneficial.

Confidentiality
The identity of participants is kept secret when researchers report or write up their findings.

Deception
A violation of the right to informed consent that may sometimes mislead participants as to the study purpose.

Ethical research
Research that is designed and conducted validly, reliably, legitimately, and representatively, and protects a research participant's rights.

Human subjects protection
Ethical research rules that refer to the guidelines that are followed to ensure the protection of people (participants) being studied.

Informed consent
This process assumes that the research participant is competent to consent—that, if he or she is given all relevant information, he or she will be able to comprehend the information and be able to agree to participate in a voluntary manner free from coercion.

Justice
All classifications of people (race, ethnicity, gender, age, etc.) should be equally subjected to the risks and benefits of research, and people should be included or excluded only for reasons that have to do with the research question or hypothesis.

Legitimation
The question of who can represent another person in narrative writing.

Member checks
The process of providing study participants with the research findings, and giving them the opportunity to voice agreement or disagreement with the research as reported.

Nonmaleficence
No avoidable harm should be done to participants.

Nuremberg Code
The first set of principles outlining professional ethics for medical researchers, which forms the basis for today's research ethics codes. It specifically required voluntary consent among research participants, and was the first international standard for the conduct of research.

Participatory action research
An example of one methodology that attempts to break down power relationships between the researcher and the researched by letting the stakeholders define the problem and work toward solutions; inviting participants to formulate the original questions, design the methodology, facilitate the sessions, and lead the analysis efforts; and moving the research into the community.

Relational ethics
The value placed on the relationships between researchers and the people they are researching.

Representation
Fully understanding the lived experiences of research participants and including the multiple realities, interpretations, experiences, and voices emergent from all individuals and all angles.

Research ethics
The specific principles, rules, guidelines, and norms of research-related behavior that a research community has decided are proper, fair, and appropriate.

Respect for persons
Research participants should be treated as autonomous agents—that means they are independent, self-governing, and capable of making decisions for themselves as long as they are given sufficient information to make those decisions.

Vulnerable populations
Persons with diminished autonomy; specifically, children, people with cognitive impairments, older adults, people with severe health problems, employees, and students.

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